



21 in the NPCS program, the Defendant's policy is to reduce the existing medical funding for in-home shift nursing services by approximately 50% based solely on the fact that the person is now 21 years of age. The reduction in funding for in-home shift nursing services is not due to a change in the Plaintiffs and putative Class medical needs but on the fact that their funding at age 21 comes from a different State program, the Illinois Home Services Program (HSP), which has significant monetary caps on funding. The reduction in funding will either result in the Plaintiffs and Class becoming institutionalized or if they remain in their family home without sufficient in-home shift nursing services, then they face a strong possibility of imminent death or a life threatening episode.

2. Prior to the filing of this lawsuit by the Plaintiff, the Defendant has been successfully challenged by individual plaintiffs in 5 separate lawsuits over its practice and policy of reducing medical funding which results in a reduction of medical services when the disabled person turns 21 years of age.<sup>1</sup>

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<sup>1</sup> Three Federal District Courts found that the Defendant violated the ADA and RA by reducing funding for medically fragile plaintiffs when they turned 21 years of age. See *Radaszewski v. Maram*, 2008 U.S. Dist. LEXIS 24923, \*37-41 (N.D. Ill. 2008) (J. Darrah); *Grooms v. Maram*, 563 F.Supp.2d 840 (N.D. Ill. 2008) (J. Pallmeyer); and *Sidell v. Maram*, 2009 U.S. Dist. LEXIS 131324 (C.D. Ill. 2009) (J. McDade).

Two other medically fragile plaintiffs have prevailed against the Defendant in Illinois. See: *Jones v. Maram*, 867 N.E.2d 563 (3<sup>rd</sup> Dist. 2007) (Illinois Appellate Court affirming lower court granting of preliminary injunction for plaintiff who aged out of a medically fragile program and was at-risk of institutionalization); *Fisher v. Maram*, 06 C 4405 (N.D. Ill.) (January 8, 2009 - Doc. 118) (J. Guzman) (enjoining Defendant from reducing services for plaintiff who aged out of a medically fragile program).

3. In *Hampe v. Hamos*, No. 10 C 3121 (N.D. Ill.) (October 3, 2013) a Consent Decree was entered on behalf of a class of “[a]ll persons who are enrolled or will be enrolled or were enrolled in the State of Illinois’ Medically Fragile, Technology Dependent Medicaid Waiver Program (MF/TD) and when they obtain the age of 21 years are subjected to reduced Medicaid funding which reduces the medical level of care which they had been receiving prior to obtaining 21 years.” (Doc. 240 at par. 5). The terms of the Consent Decree provide that a “class member’s need, level and amount of medical services will be based upon medical necessity, not the chronological age of the class member”. (*Id.* at par. 12). The instant case seeks class action status on behalf of the other group of medically fragile persons in Illinois who are enrolled in the NPCPS program. Persons in the NPCPS program are not enrolled in the MF/TD Waiver and are not part of the class in *Hampe*.

4. Despite the fact that the Defendant has not prevailed to provide reduced medical funding in these 5 separate federal and state lawsuits as well as the *Hampe* class action Consent Decree brought by similarly situated persons like the Plaintiffs who are turning 21, the Defendant continues the same unlawful and discriminatory practice today, by reducing medical funding at age 21 as evidence by the Plaintiffs case. Accordingly, the Plaintiffs brings this lawsuit seeking declaratory and injunctive relief to prevent the Defendant from reducing the level of funding for medical care currently provided to the Plaintiffs and the putative Class, which is necessary to prevent institutionalization, which is a more costly and a more restrictive setting than the current home placement. Additionally, the Plaintiffs bring this lawsuit seeking declaratory and injunctive relief to stop the Defendant from discriminating between disabled persons aging out of the NPCPS program and disabled persons aging out of the MFTD Waiver

program, by not providing in-home shift nursing services based on medical necessity to those persons aging out of the NPCCS program. This disparate treatment of comparably situated persons is a violation of the Americans with Disabilities Act.<sup>1</sup>

5. This class action lawsuit is necessary in order to stop the Defendant from continuing to systematically violate the Americans with Disabilities Act and the Rehabilitation Act for persons aging out of the “NPCCS” program and turning 21 years of age and facing significant reductions in their funding which places them at risk of either institutionalization or death.

6. Additionally, this class action lawsuit is necessary in order to stop the Defendant from discriminating between disabled persons aging out of the NPCCS program and disabled persons aging out of the MFTD Waiver program, as the Defendant treats those disabled persons aging out of the NPCCS program worse than those disabled persons aging out of the MFTD program. The Defendant permits persons aging out of the MFTD Waiver program to continue to receive in-home shift nursing service based on medical necessity while the Defendant does not permit persons aging out of the NPCCS program to receive in-home shift nursing services based on medical necessity. Defendant provides greater Medicaid benefits of in-home shift nursing services to those persons who age out of the MFTD Waiver program at age 21 than to those persons who age out of the NPCCS program at age 21, despite the fact that the persons who age out of the NPCCS program at age 21 have similar and comparable needs for in-home shift nursing services.

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<sup>1</sup> The Supreme Court held that “discrimination” under § 12132 included “not only disparate treatment of comparably situated persons but also undue institutionalization of disabled persons, not matter how anyone else is treated.” *Amundson ex rel. Amundson v. Wisconsin Dep’t of Health Servs.*, 721 F.3d 871, 874 (7<sup>th</sup> Cir. 2013) (citing *Olmstead*, 527 U.S. 581, 597-603 (1999))

7. Due to the failure of the Defendant to provide in-home shift nursing services at the level which is medically necessary, the Plaintiffs Campbell, Eaton and Tana, individually (and not on behalf of a class) are seeking monetary damages against the Defendant under the Rehabilitation Act as the result of the aggravation of their existing mental, emotional and physical conditions.

## **II. JURISDICTION & VENUE**

8. This is an action for declaratory and injunctive relief to enforce the rights of the Plaintiff and the class he seeks to represent under the Americans with Disabilities Act, 42 U.S.C. Sec. 12132 and Section 504 of the Rehabilitation Act, 29 U.S.C. Sec. 794(a).

9. This Court has jurisdiction over Plaintiffs' federal law claims pursuant to 28 U.S.C. §§ 1331 and 1343, which grant this Court original jurisdiction in all actions authorized by 43 U.S.C. § 1983 to redress the deprivation under color of state law any rights, privileges, or immunities guaranteed by the United States Constitution and Acts of Congress. The Plaintiffs' and Class' claims for declaratory and injunctive relief are authorized under 28 U.S.C. §§ 2201-02 and 42 U.S.C. § 1983.

10. Venue is proper in the Northern District of Illinois under 28 U.S.C. § 1391(b) because a substantial part of the events or omissions giving rise to Plaintiffs' claims occurred here and because Defendant Norwood may be found here.

## **III. PARTIES**

### **Plaintiff Blake Donegan**

11(a). The Plaintiff, Blake Donegan, turned 21 years of age on February 28, 2016. Blake is medically fragile and currently receives funding from the Defendant for approximately

14 hours a day of in-home shift nursing services at his home (98 hours per week). These nursing services are either provided by a registered nurse (RN) or a licensed practical nurse (LPN).

11(b). Blake has diagnoses of Niemann-Pick Disease Type C and refractory epilepsy which is difficult to control. Blake has ongoing seizures, an abnormal gait and polycystic kidney disease. Due to the severity of Blake's medical conditions, Blake requires round the clock care and supervision.

11(c). A skilled nursing level of care is required for Blake.

11(d). The alternative to Blake's skilled nursing care at his residence is hospitalization / institutionalization.

11(e). Blake resides with his mother, Angela Donegan in LaGrange Park, Illinois. Pursuant to FRCP 17(c), Blake brings this action through his mother and next friend, Angela Donegan.

**Plaintiff Antonio Campbell**

12(a). The Plaintiff, Antonio Campbell, turned 21 years of age on May 13, 2015. Antonio is medically fragile and prior to him turning 21 years of age, he received funding from the Defendant for approximately 8 hours a day of in-home shift nursing services at his home (56 hours per week). These nursing services were either provided by a registered nurse (RN) or a licensed practical nurse (LPN).

12(b). Antonio has diagnoses of subglottic stenosis, tracheostomy dependent, traumatic brain injury, hemiplegia and developmental delay. Due to the severity of Antonio's medical conditions, Antonio requires round the clock care and supervision.

12(c). A skilled nursing level of care is required for Antonio.

12(d). The alternative to Antonio's skilled nursing care at his residence is institutionalization.

12(e). Antonio resides with his mother, Shaneatha Rolling in Chicago, Illinois. Pursuant to FRCP 17(c), Antonio brings this action through his mother and next friend, Shaneatha Rolling.

**Plaintiff Janelle Eaton**

13(a). The Plaintiff, Janelle Eaton, turned 21 years of age on December 21, 2015. Janelle is medically fragile and prior to her turning 21 years of age, she received funding from the Defendant for approximately 10 hours a day of in-home shift nursing services at her home (70 hours per week). These nursing services were either provided by a registered nurse (RN) or a licensed practical nurse (LPN).

13(b). Janelle has diagnoses of Down's syndrome, hypertension, S/P renal transplant, obstructive sleep apnea and asthma. Janelle receives BiPAP at night for obstructive sleep apnea. Due to the severity of Janelle's medical conditions, Janelle requires round the clock care and supervision.

13(c). A skilled nursing level of care is required for Janelle.

13(d). The alternative to Janelle skilled nursing care at her residence is institutionalization.

13(e). Janelle resides with her mother, Jacqueline Eaton, in Dolton, Illinois. Pursuant to FRCP 17(c), Janelle brings this action through his mother and next friend, Jacqueline Eaton.

**Plaintiff Derek Tan**

14(a). The Plaintiff, Derek Tan, turned 21 years of age on January 11, 2015. Derek is medically fragile and prior to his turning 21 years of age, he received funding from the Defendant for approximately 10 hours a day of in-home shift nursing services at his home (70 hours per week). These nursing services were either provided by a registered nurse (RN) or a licensed practical nurse (LPN).

14(b). Derek has diagnoses of Duchenne's Muscular Dystrophy, dilated cardiomyopathy and obstructive sleep apnea. Derek's prognosis is poor as Duchenne's Muscular Dystrophy is an incurable, progressively worsening, neuromuscular disorder. Derek requires a BiPAP machine and oxygen nightly with sleep. As Derek's respiratory ability declines, he will likely require a tracheostomy and mechanical ventilation. Due to the severity of Derek's medical conditions, Derek requires round the clock care and supervision.

14(c). A skilled nursing level of care is required for Derek.

14(d). The alternative to Derek skilled nursing care at his residence is institutionalization.

14(e). Derek resides with his mother, Audrey Tan, in Salem, Illinois. Pursuant to FRCP 17(c), Derek brings this action through his mother and next friend, Audrey Tan.

**Plaintiff Kina Wines**

15(a). The Plaintiff, Kina Wines, turned 21 years of age on November 15, 2016. Kina is medically fragile and prior to her turning 21 years of age, she received funding from the Defendant for approximately 8 hours a day of in-home shift nursing services at her home (56 hours per week). These nursing services were either provided by a registered nurse (RN) or a licensed practical nurse (LPN).



15(b). Kina has diagnoses of H/O Medulloblastoma treated with chemotherapy, radiation and V-P shunt placement; muscle weakness, chorea, lack of coordination, obstructive sleep apnea and seizure disorder. Kina is on CPAP at night for obstructive sleep apnea. Due to the severity of Kina's medical conditions, Kina requires round the clock care and supervision.

15(c). A skilled nursing level of care is required for Kina.

15(d). The alternative to Kina skilled nursing care at his residence is institutionalization.

15(e). Kina resides with her mother, Sharon Quinn, in Chicago, Illinois. Pursuant to FRCP 17(c), Kina brings this action through his mother and next friend, Sharon Quinn.

**Defendant Felicia F. Norwood**

16. The Defendant, Felicia F. Norwood, is the Director of the Illinois Department of Healthcare and Family Services (HFS). As such she is responsible for the supervision and oversight of HFS medical programs and contractual arrangements. Her responsibilities in this role include the responsibility to ensure compliance with federal law. She is being sued in her official capacity.

**IV. CLASS ACTION ALLEGATIONS**

17. Plaintiffs bring this action on behalf of themselves and as a class action pursuant to Rule 23(b)(2) of the Federal Rules of Civil Procedure. This action is brought as a statewide class action pursuant to Fed. R. Civ. P. 23(a) and (b)(2) on behalf of:

All Medicaid-enrolled children under the age of 21 in the State of Illinois who receive in-home shift nursing services or had received in-home shift nursing services, and when they obtain the age of 21 years are subjected to reduced Medicaid funding which reduces the medical level of care which they had been receiving prior to obtaining 21 years. This class definition does not include those persons who are enrolled in the State of Illinois' Medically Fragile Technology Dependent (MFTD) Medicaid Waiver program.

18. The Class is so numerous that joinder of all persons is impracticable. As of April 1, 2016, approximately 411 children with extensive medical needs received in-home shift nursing services through the Defendant's program commonly referred to as the Nursing and Personal Care Services (NPCS) program.

19. It is also notable that Plaintiffs and Class, as participants in the Medicaid program, have limited financial resources and therefore may be less likely to institute individual actions.

20. The claims of the class members raise common questions of law and fact. These include:

(a) Whether the Defendant violated the ADA and Rehabilitation Act by reducing the level of funding for persons receiving in-home shift nursing services through the Defendant's program commonly referred to as the Nursing and Personal Care Services (NPCS) program which resulted in a reduction of medical services.

(b) Whether the Defendant discriminates against the Plaintiffs and putative Class by treating them worse than persons with other disabilities.

(c) Whether the Defendant discriminates against the Plaintiffs and putative Class when they age out of the NPCS program at age 21, as they receive disparate treatment from those persons who age out of the MFTD Waiver program at age 21.

(d) Whether the Defendant by providing Medicaid benefits of in-home shift nursing services based on medical necessity to those persons aging out of the MFTD Waiver program and not providing in-home shift nursing services based on medical necessity to those persons aging out of the NPCS program is unlawful discrimination under the ADA.

(e) Whether the ADA and Rehabilitation Act permits the Defendant to reduce the level of funding which results in a reduction of medical services for disabled persons after the age of 21, even though there has been no change in their medical needs.

(f) Whether a fundamental alteration of the Illinois disability programs would occur if the Defendant provided funding to continue the same level of services for the Plaintiff and the putative class when they turn the age of 21 years.

(g) Whether the Illinois disability programs can reasonably accommodate a modification to their existing programs to allow the Plaintiffs and putative class to continue to receive the same level of care in the community when they turn the age of 21 years.

(h) Whether compelling an increase in the level of funding for persons exiting the NPCS program into the Illinois Home Services Program is unreasonable under the ADA and Rehabilitation Act.

The common questions of fact and law predominate over questions affecting only individual class members.

21. The Plaintiffs claim are typical of the class members' claims.

22. The Plaintiffs will fairly and adequately represent the class because they suffer from deprivation identical to those of the Class members and have been denied the same federal rights that they seek to enforce on behalf of the other Class members.

23. The Plaintiffs will fairly and adequately represent the interests of the other Class members, many of whom are unable to pursue claims on their own behalf as the result of their disabilities.

24. Plaintiffs interest in obtaining injunctive relief for the violations of constitutional rights and privileges are consistent with and not antagonistic to those of any person within the Class.

25. Plaintiffs counsel are qualified, experienced and able to conduct the proposed litigation.

26. Prosecution of separate actions by individual Class members would create a risk of inconsistent or varying adjudications with respect to individual Class members, which would establish incompatible standards of conduct for the party opposing the Class or could be dispositive of the interests of the other members or substantially impair or impede the ability to protect their interests.

27. A class action is superior to other available methods for the fair and efficient adjudication of the controversy in that:

(a) A multiplicity of suits with consequent burden on the courts and defendants should be avoided.

(b) It would be virtually impossible for all Class members to intervene as parties-plaintiffs in this action.

28. The Defendant has acted or refused to act on grounds applicable to the Class, thereby making appropriate final injunctive and declaratory relief with respect to the Class as a whole.

## **V. STATUTORY AND REGULATORY FRAMEWORK**

### **A. The Americans with Disabilities Act (ADA) and Implementing Regulations**

29. In enacting the Americans with Disabilities Act, Congress prohibited outright discrimination and “identified unjustified ‘segregation’ of persons with disabilities as a ‘for[m]

of discrimination.” *Olmstead*, 527 U.S. at 600 (quoting § 12101(a)(2)). “Unjustified isolation” is therefore “properly regarded as discrimination based on disability.” *Id.* at 597. The Supreme Court held that “discrimination” under § 12132 included “not only disparate treatment of comparably situated persons but also undue institutionalization of disabled persons, no matter how anyone else is treated.” *Amundson ex rel. Amundson v. Wisconsin Dep’t of Health Servs.*, 721 F.3d 871, 874 (7<sup>th</sup> Cir. 2013) (citing *Olmstead*, 527 U.S. at 597-603).

30. Title II of the Americans with Disabilities Act provides that “no qualified individual with a disability shall, by reason of disability, be excluded from participation in or be denied the benefits of services, programs, or activities of a public entity or be subjected to discrimination by such entity.” 42 U.S.C. Sec. 12132.

31. Regulations implementing Title II of the ADA make clear that the ADA requires that: “A public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.” 28 C.F.R. Sec. 35.130(d).

32. Regulations implementing Title II of the ADA provide: “A public entity may not, directly or through contractual or other arrangements, utilize criteria or other methods of administration: (i) that have the effect of subjecting qualified individuals with disabilities to discrimination on the basis of disability; [or] (ii) that have the purpose or effect of defeating or substantially impairing accomplishment of the objectives of the entity’s program with respect to individuals with disabilities. . . .” 28 C.F.R. Sec. 35.130(b)(3).

33. Regulations implementing Title II of the ADA provides that a public entity is not only prohibited from affording to persons with disabilities services that are “not equal to that

afforded other,” 28 C.F.R. Sec. 35.130(b)(1)(ii), or “not as effective in affording equal opportunity,” *Id.* Sec. 35.130(b)(1)(iii), but also cannot prevent a qualified individual with a disability from enjoying “any aid, benefit, or service,” *Id.* Sec. 35.130(b)(1)(i), regardless of whether other individuals are granted access.

34. The United States Supreme Court in *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581 (1999), held that the unnecessary institutionalization of individuals with disabilities is a form of discrimination under Title II of the ADA. In doing so, the Supreme Court interpreted the ADA’s “integration mandate” to require that persons with disabilities be served in the community when: (1) the state determines that community-based treatment is appropriate; (2) the individual does not oppose community placement; and (3) community placement can be reasonably accommodated. *Id.* at 607.

#### **The Section 504 of the Rehabilitation Act and Implementing Regulations**

35. Section 504 of the Rehabilitation Act of 1973 (Rehabilitation Act), on which the ADA is modeled, sets forth similar protections against discrimination by recipients of federal funds, such as the Defendant. 29 U.S.C. Secs. 794-794a. These protections include the prohibition against unnecessary segregation of people with disabilities. Regulations implementing the Rehabilitation Act require that a public entity administer its services, programs and activities in “the most integrated setting appropriate” to the needs of qualified individuals with disabilities. 28 C.F.R. Sec. 41.51(d).

### **VI. STATEMENT OF FACTS**

#### **A. The Federal/State Medical Assistance Program**

36. Medical Assistance, commonly known as Medicaid, is a joint federal and state funded program enacted to provide necessary medical assistance to needy aged or disabled persons and families with dependent children, whose income and resources are insufficient to meet the cost of care. 42 U.S.C. Sec. 1396. States choosing to participate in the Medicaid program must operate the program in conformity with federal statutory and regulatory requirements. 42 U.S.C. Sec. 1396a.

37. Each State participating in the Medicaid program must submit a Medicaid plan to the Secretary of Health and Human Services (HHS) for approval. 42 U.S.C. Sec. 1396.

38. Each State must designate a single state agency to administer and / or supervise the administration of the state's Medicaid plan. 42 U.S.C. Sec. 1396a(a)(5).

39. In Illinois, the Department of Healthcare and Family Services (HFS) is the single state agency responsible for administering the Medicaid program.

40. States have the option of covering persons needing home-and-community-based services, if these persons would otherwise require institutional care that would be paid for by Medicaid. 42 U.S.C. Sec. 1396n(c)(1). Under this waiver authority, the Secretary of HHS may grant waivers of specified requirements like service limitations that are otherwise applicable to the State's Medicaid plan. 42 U.S.C. Sec. 1396n(c)(3). Waiver programs must be cost-neutral in that the average cost of providing care for program participants in the home or community based setting must not exceed the estimated average cost of providing care in the institutional setting they would require. 42 U.S.C. Sec. 1396n(c)(2)(D); 42 C.F.R. Sec. 441.302(e).

41. Illinois has implemented a total of nine (9) federally approved home-and-community-based care waiver programs in its Medicaid program which were approved by the Secretary of Health & Human Services (HHS). Two of the nine waiver programs are as follows:

- Children that are Technology Dependent / Medically Fragile (MFTD)
- Persons with Disabilities (Home Services for Adults with Disabilities) (HSP)

**B. Nursing and Personal Care Services (NPCS) Program For Children Under Age 21.**

42. With respect to the NPCS Program for children under the age of 21, the Illinois Department of Healthcare and Family Services (HFS) Division of Medical Program provides services to children under age 21 who have been determined to have extensive medical needs, requiring ongoing skilled nursing in the home setting. Children must meet Medicaid eligibility and live in a private home. Children receiving this NPCS may not be concurrently receiving services under the Medically Fragile, Technology Dependent (MFTD) Home and Community-Based Services (HCBS) waiver. Services are prior approved initially for 60 days with two 50-day renewal periods. After the first 180 days of service, cases are reviewed on 6-month or annual schedules depending on the medical stability of the child. Services are provided by approved Home Nursing Agencies licensed by the Department of Public Health.

43. The eligibility criteria for the NPCS program is as follows:
- a) Children under the age of 21 who have extensive medical needs and require ongoing skilled nursing care as determined by the Department's prior approval process.
  - b) U.S. Citizen or legal alien.
  - c) Be a resident of the State of Illinois.
  - d) Under age 21.



- e) Eligible for the Medical Assistance Program.
- f) Prior approved for services by the Department.
- g) Physician order and justification for services.

**C. Medically Fragile Technology Dependent Waiver Program (MFTD).**

44. Under the waiver program for Medically Fragile, Technology Dependent Children, Illinois pays for home-based care for children under age 21 who have exceptional medical needs. The Illinois Department of Healthcare and Family Services (HFS) administers this waiver program with participation of the University of Illinois' Division of Specialized Services for Children (DSCC) under an agreement with HFS.

45. The Illinois Medicaid Home and Community-Based Services ("HCBS") waiver program, which includes the MFTD program, allows the State of Illinois to provide services to persons, like the Plaintiffs, in an individual's home or community as long as those services prevent the individual from being institutionalized or hospitalized.

46. The MFTD waiver for children serves persons under 21 years of age who would require institutional care in a hospital or nursing facility, if nursing and waiver services were not provided in the home. Cost-effectiveness for eligibility is compared to service costs in a hospital or nursing facility. The primary expenditure for children in the MFTD waiver is skilled nursing.

**D. Persons with Disabilities (Home Services Program) (HSP)**

47. Under the Home Services waiver program (HSP), Illinois funds services to enable disabled adults to remain in their homes or in a community setting. The Illinois Department of Healthcare and Family Services (HFS) administers the HSP program with the participation of the Division of Rehabilitative Services (DRS) of the Illinois Department of

Human Services (DHS) through an agreement with HFS. The HSP program has significant monetary caps on the level of funding which is available to the Plaintiffs and Class, which results in an approximate reduction of funding by 50% when the Plaintiffs and Class turn 21 years of age and age out of the NPCCS program and move into the HSP program.

**E. Defendant Discriminates Against the Plaintiffs and Class When They Age Out of the NPCCS Program at Age 21**

48. The Defendant provides in-home shift nursing services to persons in both the NPCCS and MFTD Waiver program under the age of 21 years. However, the Defendant provides all persons who age out of the MFTD Waiver program at the age of 21 years with in-home shift nursing services which is at or near the same level of in-home shift nursing services when they turned 21 years of age. In contrast, Defendant will not provide all persons who age out of the NPCCS program at the age of 21 years with in-home shift nursing services which is at or near the same level of in-home shift nursing services when they turned 21 years of age.

49. Defendant provides in-home shift nursing services to those persons who age out of the MFTD Waiver program at a level which favors and discriminates against those persons who age out of the NPCCS program.

50. Defendant's practice and policy is to provide in-home shift nursing services to those persons who age out of the MFTD Waiver program based on medical necessity.

51. Defendant's practice and policy is not to provide in-home shift nursing services to those persons who age out of the NPCCS program based on medical necessity.

52. Defendant provides greater Medicaid benefits of in-home shift nursing services to those persons who age out of the MFTD Waiver program at age 21 than to those persons who age out of the NPCCS program at age 21.

53. Defendant provides greater Medicaid benefits of in-home shift nursing services to those persons who age out of the MFTD Waiver program at age 21 than to those persons who age out of the NPCCS program at age 21, despite the fact that the persons who age out of the NPCCS program at age 21 have similar and comparable needs for in-home shift nursing services.

**F. Plaintiff Blake Donegan**

54. The Plaintiff, Blake Donegan, turned 21 years of age on February 28, 2016. Blake is medically fragile and currently receives funding from the Defendant for approximately 14 hours a day of in-home shift nursing services at his home (98 hours per week). The in-home shift nursing services provided to Blake are through the NPCCS program and are medically necessary. These nursing services are either provided by a registered nurse (RN) or a licensed practical nurse (LPN).

55. Blake has diagnoses of Niemann-Pick Disease Type C and refractory epilepsy which is difficult to control. Blake has ongoing seizures, an abnormal gait and polycystic kidney disease. Due to the severity of Blake's medical conditions, Blake requires round the clock care and supervision.

56. A skilled nursing level of care is required for Blake.

57. The alternative to Blake's in-home shift nursing services at his residence is hospitalization / institutionalization.

58. Blake's current funding from the Defendant comes from the State of Illinois Medicaid Program. Blake received in-home shift nursing services through the NPCCS Program. Blake's funding from the Defendant for in-home shift nursing services is at a cost of

approximately \$14,000 per month, so that he does not have to be institutionalized or hospitalized at a rate of approximately \$55,000 per month.

59. Blake's enrollment in the NPCCS program is only available to persons under the age of 21 and Blake turned 21 years of age on February 28, 2016.

60. When Blake turned 21 years of age on February 28, 2016, he was subjected to substantial reduced funding of his current rate and Blake will be unable to maintain the same level of intensive skilled nursing care which he needs. The State of Illinois through a representative from the Illinois Department of Human Services – Division of Rehabilitative Services, has informed Blake's mother, Angela Donegan, that when Blake turns 21 years of age, that he would be able to receive funding for in-home shift nursing services at a level which is substantially less than the current level which he received prior to his 21<sup>st</sup> birthday. The Home Services Program only provided a rate of \$10,190 per month for Blake which is referred to as an "exceptional care rate" (ECR) and the agent for the State of Illinois acknowledged that she is "certain that ECR would not meet his continued need." (HFS008730-8731) This State policy of significantly reducing funding for in-home shift nursing services, is in conflict with 5 recent Federal and State court cases, where the Defendant was not permitted to reduce funding for a medically fragile person when he or she turned 21 years of age. (See cases listed in paragraph 3 above).

61. Besides Blake's funding for in-home shift nursing services of approximately 98 hours per week, he also receives funding for a personal assistant through the Illinois Department of Human Services, Home Services Program (HSP). Personal assistant services provide care to Blake when a nurse is not present during any 24 hour period. (If Blake received 8 hours of in-

home shift nursing services on a given day, then he could receive 16 hours of personal assistant services on that same day). Blake needs funding for both in-home shift nursing services and personal assistant services to provide 24/7 care.

62. If Blake is unable to receive the current level of in-home shift nursing services in his home and home health care services (personal assistant), then he would be forced to be institutionalized and obtain medical care in a hospital setting at a rate of approximately \$55,000 per month, which costs more than his current level of funding in the family home.

63. Blake is requesting declaratory and injunctive relief to require the Defendant to provide funding for in-home shift nursing services at the same level which he had prior to his 21<sup>st</sup> birthday. The actions of the Defendant constitute unlawful discrimination under Title II of the Americans with Disabilities (ADA), 42 U.S.C. Sec. 12132, and Section 504 of the Rehabilitation Act, 29 U.S.C. Sec. 794(a).

64. Blake is an individual with a disability.

65. Blake is a recipient of Medical Assistance, commonly known as Medicaid.

**G. Plaintiff Antonio Campbell**

66. The Plaintiff, Antonio Campbell, turned 21 years of age on May 13, 2015. Antonio is medically fragile and prior to him turning 21 years of age, he received funding from the Defendant for approximately 8 hours a day of in-home shift nursing services at his home (56 hours per week). These nursing services were either provided by a registered nurse (RN) or a licensed practical nurse (LPN).

67. Antonio has diagnoses of subglottic stenosis, tracheostomy dependent, traumatic brain injury, hemiplegia and developmental delay. Due to the severity of Antonio's medical conditions, Antonio requires round the clock care and supervision.

68. A skilled nursing level of care is required for Antonio.

69. The alternative to Antonio's skilled nursing care at his residence is institutionalization.

70. Antonio's current funding from the Defendant comes from the State of Illinois Medicaid Program. Antonia received in-home shift nursing services through the NPCPS Program. Antonio's funding from the Defendant for in-home shift nursing services is at a cost of approximately \$8,523 per month, so that he does not have to be institutionalized or hospitalized at a rate of approximately \$55,000 per month.

71. Antonio's enrollment in the NPCPS program is only available to persons under the age of 21 and Antonio turned 21 years of age on May 13, 2015.

72. When Antonio turned 21 years of age on May 13, 2015, he is subjected to reduced funding at approximately 50% of his current rate and Antonio will be unable to maintain the same level of intensive skilled nursing care which he needs. Antonio sought funding after his 21<sup>st</sup> birthday through the Illinois Department of Human Services, Home Services Program (HSP) and was denied services despite the fact that his medical condition did not change when he turned 21 years of age.

73. Antonio is requesting declaratory and injunctive relief to require the Defendant to provide funding for in-home shift nursing services at the same level which he had prior to his 21<sup>st</sup> birthday. The actions of the Defendant constitute unlawful discrimination under Title II of

the Americans with Disabilities (ADA), 42 U.S.C. Sec. 12132, and Section 504 of the Rehabilitation Act, 29 U.S.C. Sec. 794(a).

74. Antonio is an individual with a disability.

75. Antonio is a recipient of Medical Assistance, commonly known as Medicaid.

#### **H. Plaintiff Janelle Eaton**

76. The Plaintiff, Janelle Eaton, turned 21 years of age on December 21, 2015. Janelle is medically fragile and prior to her turning 21 years of age, she received funding from the Defendant for approximately 10 hours a day of in-home shift nursing services at her home (70 hours per week). These nursing services were either provided by a registered nurse (RN) or a licensed practical nurse (LPN).

77. Janelle has diagnoses of Down's syndrome, hypertension, S/P renal transplant, obstructive sleep apnea and asthma. Janelle receives BiPAP at night for obstructive sleep apnea. Due to the severity of Janelle's medical conditions, Janelle requires round the clock care and supervision.

78. A skilled nursing level of care is required for Janelle.

79. The alternative to Janelle skilled nursing care at her residence is institutionalization.

80. Janelle's current funding from the Defendant comes from the State of Illinois Medicaid Program. Janelle received in-home shift nursing services through the NPCPS Program. Janelle's funding from the Defendant for in-home shift nursing services is at a cost of approximately \$10,761 per month, so that she does not have to be institutionalized or hospitalized at a rate of approximately \$55,000 per month.

81. Janelle's enrollment in the NPCS program is only available to persons under the age of 21 and Janelle turned 21 years of age on December 21, 2015.

82. When Janelle turned 21 years of age on May 13, 2015, she is subjected to reduced funding at approximately 50% of her current rate and Janelle will be unable to maintain the same level of intensive skilled nursing care which she needs. Janelle sought funding after her 21<sup>st</sup> birthday through the Illinois Department of Human Services, Home Services Program (HSP) and to date, the Illinois Department of Human Services has refused to respond to her repeated requests for services / funding.

83. Janelle is requesting declaratory and injunctive relief to require the Defendant to provide funding for in-home shift nursing services at the same level which she had prior to his 21<sup>st</sup> birthday. The actions of the Defendant constitute unlawful discrimination under Title II of the Americans with Disabilities (ADA), 42 U.S.C. Sec. 12132, and Section 504 of the Rehabilitation Act, 29 U.S.C. Sec. 794(a).

84. Janelle is an individual with a disability.

85. Janelle is a recipient of Medical Assistance, commonly known as Medicaid.

#### **I. Plaintiff Derek Tan**

86. The Plaintiff, Derek Tan, turned 21 years of age on January 11, 2015. Derek is medically fragile and prior to his turning 21 years of age, he received funding from the Defendant for approximately 10 hours a day of in-home shift nursing services at his home (70 hours per week). These nursing services were either provided by a registered nurse (RN) or a licensed practical nurse (LPN).



87. Derek has diagnoses of Duchenne's Muscular Dystrophy, dilated cardiomyopathy and obstructive sleep apnea. Derek's prognosis is poor as Duchenne's Muscular Dystrophy is an incurable, progressively worsening, neuromuscular disorder. Derek requires a BiPAP machine and oxygen nightly with sleep. As Derek's respiratory ability declines, he will likely require a tracheostomy and mechanical ventilation. Due to the severity of Derek's medical conditions, Derek requires round the clock care and supervision.

88. A skilled nursing level of care is required for Derek.

89. The alternative to Derek skilled nursing care at his residence is institutionalization.

90. Derek's current funding from the Defendant comes from the State of Illinois Medicaid Program. Derek received in-home shift nursing services through the NPCPS Program. Derek's funding from the Defendant for in-home shift nursing services is at a cost of approximately \$8,833 per month, so that he does not have to be institutionalized or hospitalized at a rate of approximately \$55,000 per month.

91. Derek's enrollment in the NPCPS program is only available to persons under the age of 21 and Derek turned 21 years of age on January 11, 2015.

92. When Derek turned 21 years of age on January 11, 2015, he is subjected to reduced funding at approximately 50% of his current rate and Derek will be unable to maintain the same level of intensive skilled nursing care which he needs. Derek sought funding after his 21<sup>st</sup> birthday through the Illinois Department of Human Services, Home Services Program (HSP) and was only approved for approximately 66 hours a week of personal attendant services (\$3,904 per month) as opposed to approval for in-home shift nursing services, despite the fact that his medical condition did not change when he turned 21 years of age.

93. Derek is requesting declaratory and injunctive relief to require the Defendant to provide funding for in-home shift nursing services at the same level which he had prior to his 21<sup>st</sup> birthday. The actions of the Defendant constitute unlawful discrimination under Title II of the Americans with Disabilities (ADA), 42 U.S.C. Sec. 12132, and Section 504 of the Rehabilitation Act, 29 U.S.C. Sec. 794(a).

94. Derek is an individual with a disability.

95. Derek is a recipient of Medical Assistance, commonly known as Medicaid.

**J. Plaintiff Kina Wines**

96. The Plaintiff, Kina Wines, turned 21 years of age on November 15, 2016. Kina is medically fragile and prior to her turning 21 years of age, she received funding from the Defendant for approximately 8 hours a day of in-home shift nursing services at her home (56 hours per week). These nursing services were either provided by a registered nurse (RN) or a licensed practical nurse (LPN).

97. Kina has diagnoses of H/O Medulloblastoma treated with chemotherapy, radiation and V-P shunt placement; muscle weakness, chorea, lack of coordination, obstructive sleep apnea and seizure disorder. Kina is on CPAP at night for obstructive sleep apnea. Due to the severity of Kina's medical conditions, Kina requires round the clock care and supervision.

98. A skilled nursing level of care is required for Kina.

99. The alternative to Kina skilled nursing care at his residence is institutionalization.

100. Kina's current funding from the Defendant comes from the State of Illinois Medicaid Program. Kina received in-home shift nursing services through the NPCPS Program. Kina's funding from the Defendant for in-home shift nursing services is at a cost of approximately

\$8,523 per month, so that she does not have to be institutionalized or hospitalized at a rate of approximately \$55,000 per month.

101. Kina's enrollment in the NPCS program is only available to persons under the age of 21 and Kina turned 21 years of age on November 15, 2016.

102. When Kina turned 21 years of age on November 15, 2016, she is subjected to reduced funding at approximately 50% of her current rate and Kina will be unable to maintain the same level of intensive skilled nursing care which she needs.

103. Kina is requesting declaratory and injunctive relief to require the Defendant to provide funding for in-home shift nursing services at the same level which she had prior to his 21<sup>st</sup> birthday. The actions of the Defendant constitute unlawful discrimination under Title II of the Americans with Disabilities (ADA), 42 U.S.C. Sec. 12132, and Section 504 of the Rehabilitation Act, 29 U.S.C. Sec. 794(a).

104. Kina is an individual with a disability.

105. Kina is a recipient of Medical Assistance, commonly known as Medicaid.

## **VII. CAUSES OF ACTION**

### **COUNT I**

#### **VIOLATION OF AMERICAN WITH DISABILITIES ACT (ADA) AND 42 U.S.C SECTION 1983**

106. The Plaintiffs incorporate and re-allege paragraphs 1-105 as if fully set forth herein.

107. Title II of the American with Disabilities Act (ADA) provides that no qualified person with a disability shall be subjected to discrimination by a public entity. 42 U.S.C. Sec. 42 U.S.C. Sec. 12132. A public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities. 28 C.F.R.

Sec. 35.130(d) (1998). Policies and practices that have the effects of unjustifiably segregating persons with disabilities in institutions constitute prohibited discrimination under the ADA.

108. Policies and practices which result in disparate treatment of comparably situated disabled persons constitutes prohibited discrimination under the ADA.

109. The Plaintiffs are qualified individuals with disabilities within the meaning of Title II of the ADA.

110. The Illinois Department of Healthcare and Family Services of which Defendant Norwood is Director is a “public entity” within the meaning of Title II of the ADA.

111. The actions by HFS constitute unlawful discrimination under 42 U.S.C. Sec. 12132 and violate the integration mandate of the regulations implementing this statutory prohibitions. 28 C.F.R. Sec. 35.130(d).

112. The Defendant’s planned reduced funding or actual reduced funding of the in-home shift nursing services which the Plaintiffs need in order to avoid institutionalization, violates Title II of the ADA, 42 U.S.C. Sec. 12132 and its implementing regulation. 28 C.F.R. Sec. 35.130(d).

113. The Defendant’s disparate treatment of the Plaintiffs and putative Class aging out of the NPCPS program in contrast to those persons aging out of the MFTD Waiver program constitute unlawful discrimination under 42 U.S.C. Sec. 12132 as they are being treated worse than persons with other disabilities. The Defendant permits in-home shift nursing services to continue for persons aging out of the MFTD Waiver program based on medical necessity, but does not permit in-home shift nursing services to continue for persons aging out of the NPCPS program based on medical necessity.

114. The Defendant provides greater Medicaid benefits of in-home shift nursing services to those persons who age out of the MFTD Waiver program at age 21 than to those persons who age out of the NPCPS program at age 21.

115. Defendant provides greater Medicaid benefits of in-home shift nursing services to those persons who age out of the MFTD Waiver program at age 21 than to those persons who age out of the NPCPS program at age 21, despite the fact that the persons who age out of the NPCPS program at age 21 have similar and comparable needs for in-home shift nursing services.

116. The Defendant has intentionally discriminated against the Plaintiffs and Class as they are being treated worse than persons with other disabilities.

117. The Defendant has intentionally discriminated against the Plaintiffs and Class as they receive disparate treatment of comparable situated persons.

118. The Defendant has intentionally discriminated against the Plaintiffs and Class by establishing a system which requires them to become institutionalized in order to receive or access skilled nursing services, while other persons are able to access community based services (in-home shift nursing services) without having to become institutionalized.

119. The Plaintiffs and the putative class will suffer irreparable injury if the Defendant is not enjoined from reducing the funding when a person turns the age of 21 years, as the reduced level of funding will force the Plaintiffs and the putative class into an institution, where they will not receive the most integrated setting appropriate to their needs, or alternatively, the reduced level of funding and remaining at home may lead to their death or serious injury.

120. The Plaintiffs and putative class have no adequate remedy at law.

121. The Plaintiffs are indigent and unable to post bond.

**COUNT II**

**VIOLATION OF REHABILITATION ACT AND 42 U.S.C SECTION 1983  
(DECLARATORY AND INJUNCTIVE RELIEF)**

122. The Plaintiffs incorporate and re-allege paragraphs 1-121 as if fully set forth herein.

123. The Rehabilitation Act, 29 U.S.C. Sec. 794, prohibits public entities and recipients of federal funds from discriminating against any individual by reason of disability. The implementing regulation for the statute requires that public and federally-funded entities provide programs and activities “in the most integrated setting appropriate to the needs of the qualified individual with a disability.” 28 C.F.R. Section 41.51(d). Policies and practices that have the effects of unjustifiably segregating persons with disabilities in institutions constitute prohibited discrimination under the Rehabilitation Act.

124. The Illinois Department of Healthcare and Family Services is a recipient of federal funds under the Rehabilitation Act.

125. The Plaintiffs are a qualified individual with a disability under Section 504 of the Rehabilitation Act.

126. The actions by HFS constitute unlawful discrimination under 29 U.S.C. Sec. 794(a) and violate the integration mandate of the regulations implementing this statutory prohibition. 28 C.F.R. Sec. 41.51(d).

127. The Defendant’s planned reduced funding or actual reduced funding of the in-home shift nursing services which the Plaintiffs need in order to avoid institutionalization, violates Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. Sec. 794(a) and its implementing regulation. 28 C.F.R. Sec. 41.51(d).

128. The Plaintiffs and the putative class will suffer irreparable injury if the Defendant is not enjoined from reducing funding when they turn the age of 21 years, as the reduced level of funding will force the Plaintiffs and the putative class into an institution, where they will not receive the most integrated setting appropriate to his needs, or alternatively, the reduced level of funding and remaining at home may lead to their death or serious injury.

129. The Plaintiffs and putative class have no adequate remedy at law.

130. The Plaintiffs are indigent and unable to post bond.

### **COUNT III**

#### **VIOLATION OF REHABILITATION ACT (MONETARY DAMAGES AS TO PLAINTIFFS CAMPBELL, EATON, and TAN)**

131. The Plaintiffs Campbell, Eaton and Tan incorporate and re-allege paragraphs 1-130 as if fully set forth herein.

132. The Defendant provides in-home shift nursing services to persons in both the NPCCS and MFTD Waiver program under the age of 21 years. However, the Defendant provides all persons who age out of the MFTD Waiver program at the age of 21 years with in-home shift nursing services which is at or near the same level of in-home shift nursing services when they turned 21 years of age. In contrast, Defendant will not provide all persons who age out of the NPCCS program at the age of 21 years with in-home shift nursing services which is at or near the same level of in-home shift nursing services when they turned 21 years of age.

133. Defendant provides in-home shift nursing services to those persons who age out of the MFTD Waiver program at a level which favors and discriminates against those persons who age out of the NPCCS program.

134. Defendant provides greater Medicaid benefits of in-home shift nursing services to those persons who age out of the MFTD Waiver program at age 21 than to those persons who age out of the NPCCS program at age 21.

135. Defendant provides greater Medicaid benefits of in-home shift nursing services to those persons who age out of the MFTD Waiver program at age 21 than to those persons who age out of the NPCCS program at age 21, despite the fact that the persons who age out of the NPCCS program at age 21 have similar and comparable needs for in-home shift nursing services.

136. The Defendant has intentionally discriminated against the Plaintiffs Campbell, Eaton and Tan as they are being treated worse than persons with other disabilities.

137. The Defendant has intentionally discriminated against the Plaintiffs Campbell, Eaton and Tan as they receive disparate treatment of comparable situated persons.

138. The Defendant has intentionally discriminated against the Plaintiffs Campbell, Eaton and Tan by establishing a system which requires them to become institutionalized in order to receive or access skilled nursing services, while other persons are able to access community based services (in-home shift nursing services) without having to become institutionalized.

139. The Defendant has been “deliberately indifferent” to the Plaintiffs Campbell, Eaton and Tan as they are being treated worse by the Defendant than persons with other disabilities.

140. The Defendant has been “deliberately indifferent” to the need for community based in-home shift nursing services to the Plaintiffs Campbell, Eaton and Tan. Despite the demonstrated advantages of community-based programs, Defendant administers an antiquated system for serving people aging out of the NPCCS program that relies heavily on institutionalization in order to receive intensive services.



141. The Defendant has been “deliberately indifferent” to the Plaintiffs Campbell, Eaton and Tan by failing to provide a reasonable modification or accommodation to the existing institutional funding for skilled nursing services in order for the Plaintiffs Campbell, Eaton and Tan to receive funding for community based in-home shift nursing services.

142. It would not fundamentally alter the Defendant’s programs, services or activities to provide the Plaintiffs Campbell, Eaton and Tan with funding for in-home shift nursing services.

143. Providing institutional care to the Plaintiffs Campbell, Eaton and Tan would be more costly than providing community-based in-home shift nursing services to these Plaintiffs in a residential setting.

144. As a direct and proximate result of the Defendant’s policies, practices and procedures, the Plaintiffs Campbell, Eaton and Tan have been denied in-home shift nursing services which has caused emotional distress, mental anguish and physical injuries.

145. As a result of the acts and omissions of the Defendant, the Plaintiffs Campbell, Eaton and Tan have suffered and will suffer and continue to suffer mental, emotional and physical deprivation, including but not limited to the aggravation of existing mental, emotion and physical conditions.

146. As a result of the acts and omissions of the Defendant, the Plaintiffs Campbell, Eaton and Tan have suffered and will suffer and continue to suffer physical, mental and emotional deprivation, including but not limited to the loss of opportunities to develop to their fullest potential, and aggravation of their existing physical, mental and emotional conditions. The Plaintiffs Campbell, Eaton and Tan will continue to suffer such deprivations in the future absent relief from this Court.

147. The Plaintiffs Campbell, Eaton and Tan seek monetary damages, individually and not on behalf of the Class, to redress the Defendant's violation of the Rehabilitation Act.

### **VIII. REQUEST FOR RELIEF**

WHEREFORE, the Plaintiffs respectfully request that this Court:

(a) Certify this case to proceed as a class action.

(b) Issue a Declaratory Judgment in favor of the Plaintiffs and the Class and that the Defendant's reduction in funding which results in a reduction of medical services (in-home shift nursing services) when aging out of the State of Illinois Nursing and Personal Care Services (NPCS) Program violates the Americans with Disabilities Act, 42 U.S.C. Sec. 12132 and Section 504 of the Rehabilitation Act, 29 U.S.C. Sec. 794(a) and their implementing regulations, 28 C.F.R. Sec. 35.130(d), 41.51(d).

(c) Issue Preliminary and Permanent Injunctive relief requiring the Defendant to restore the level of funding to maintain the existing medical services (in-home shift nursing services) for the Plaintiffs and putative Class prior to aging out of the State of Illinois Nursing and Personal Care Services (NPCS) Program.

(d) Issue Preliminary and Permanent Injunctive relief requiring the Defendant to treat the Plaintiffs and putative Class when aging out of the NPCS program in a similar manner as the Defendant treats those persons when aging out of the MFTD Waiver program.

(e) Issue Preliminary and Permanent Injunctive relief requiring the Defendant to stop discriminating between the Plaintiffs and putative Class when aging out of the NPCS program in and those persons when aging out of the MFTD Waiver program.

(f) Award monetary damages to the Plaintiffs Campbell, Eaton and Tan under the Rehabilitation Act.

(g) Award Plaintiffs and the Class the costs of this action, including reasonable attorneys' fees, pursuant to 42 U.S.C. Section 12205; Section 504 of the Rehabilitation Act, and 42 U.S.C. Section 1988; and

(h) Award such other relief as the Court deems just and appropriate.

Respectfully submitted,

/s/ Robert H. Farley, Jr.  
Attorney for the Plaintiffs

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**CERTIFICATE OF SERVICE**

I, Robert H. Farley, Jr., Attorney for the Plaintiff, deposes and states that he caused the foregoing Plaintiffs Amended Complaint to be served by electronically filing said document with the Clerk of the Court using the CM/ECF system, this 23<sup>rd</sup> day of February, 2017.

/s/ Robert H. Farley, Jr.